

\*adopted by the Council of Multiple Birth Organizations of the International Society for Twin Studies, May 1995 (updated in 2007)

Introduction: The mission of the Council of Multiple Birth Organizations (COMBO) of the International Society for Twin Studies is to promote awareness of the special needs of multiple birth infants, children, and adults. The multi-national membership of COMBO has developed this Declaration of Rights and Statement of Needs of Twins and Higher Order Multiples as benchmarks by which to evaluate and stimulate the development of resources to meet their special needs.

**Declaration of Rights** WHEREAS myths and superstitions about the origins of multiples have resulted in the culturally sanctioned banishment and/or infanticide of multiples in some countries:

I. Multiples and their families have a right to full protection, under the law, and freedom from discrimination of any kind.

WHEREAS the conception and care of multiples increase the health and psychosocial risks of their families, and whereas genetic factors, fertility drugs, and in vitro fertilization techniques are known to promote multifetal pregnancies:

II. Couples planning their families and/or seeking infertility treatment have a right to information and education about factors which influence the conception of multiples, the associated pregnancy risks and treatments, and facts regarding parenting multiples.

WHEREAS the zygosity of same sex multiples cannot be reliably determined by their appearances; and whereas 1) the heritability of dizygotic (two-egg) twinning increases the rate of conception of multiples; 2) the similar biology and inheritance of monozygotic (one-egg) multiples profoundly affect similarities in their development; 3) monozygotic multiples are blood and organ donors of choice for their co-multiples; and 4) the availability of the placenta and optimal conditions for determining zygosity are present at birth:

III.

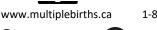
- A) Parents have a right to expect accurate recording of placentation and the diagnosis of the zygosity of the zygosity of same sex multiples at birth.
- B) Older, same sex multiples of undetermined zygosity have a right to testing to ascertain their zygosity WHEREAS during World War II twins were incarcerated in Nazi concentration camps and submitted by force to
- IV. Any research incorporating multiples must be subordinated to the informed consent of the multiples and/or their parents and must comply with international codes of ethics governing human experimentation.

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experiments which caused disease or death:



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WHEREAS inadequate documentation, ignorance, and misconceptions regarding multiples and multiple birth increase the risk of misdiagnosis and/or inappropriate treatment of multiples:

٧.

- A) Multiple births and deaths must be accurately recorded.
- B) Parents and multiples have a right to care by professionals who are knowledgeable regarding the management of multiple gestation and/or the lifelong special needs of multiples.

WHEREAS the bond between co-multiples is a vital aspect of their normal development:

VI. Co-multiples have the right to be placed together in foster care, adoptive families, and custody agreements.

### Statement of Needs

Summary: Twins, and higher order multiples have unique: conception, gestation and birth processes; health risks; impacts on the family system; developmental environments; and individuation processes. Therefore, in order to insure their optimal development, multiples and their families need access to health care, social services, and education which respect and address their differences from single born children.

WHEREAS twins and higher order multiple births are at high risk of low birth weight (<2500 grams), and very low birth weight (< 1500 grams), disability, and infant death:

- ١. Women who are expecting multiples have a need for:
- education regarding the prevention and symptoms of pre-term labor, A)
- B) prenatal resources and care designed to avert the pre-term birth of multiples, including:
- 1. diagnosis of a multiple pregnancy, ideally by the fifth month, which is communicated tactfully, with respect for the privacy of the parents;
- 2. nutrition counselling and dietary resources to support a weight gain of 18-27 kilos (40-60 pounds)
- 3. obstetrical care which follows protocols of best practice for multiple birth and when the health of the mother or family circumstances warrant:
- extended work leave; a.
- bed rest support; and b.

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- c. child care for siblings.
- 4. heightened diligence toward diagnosis and treatment (when needed) for the conditions to which multiples are uniquely at risk, including but not limited to twin-to-twin transfusion syndrome (TTTS);
- 5. attention to the timing and mode of delivery of multiples

(See References, Section I).

WHEREAS breastfeeding provides optimal nutrition and nurture for pre-term and full-term multiples; and whereas the process of breastfeeding and/or bottle feeding of multiples is complex and demanding:

- II. Families expecting and rearing multiples need the following:
- A) education regarding the nutritional, psychological, and financial benefits of breastfeeding for pre-term and full-term infants:
- B) encouragement and coaching in breastfeeding techniques;
- C) education and coached practice in simultaneous bottle feeding of co-multiples; and,
- D) adequate resources, support systems, and family work leave to facilitate the breastfeeding and/or bottle feeding process.

(See References, Section II).

WHEREAS 60% of multiples are born before 37 weeks gestation and/or at low birth weight and experience a high rate of hospitalization which endangers the bonding process and breastfeeding; and whereas newborn multiples are comforted by their fetal position together:

III. Families with medically fragile multiples need specialized education and assistance to promote and encourage bonding and breastfeeding. Hospital placement of medically fragile multiples and hospital protocols should facilitate family access, including co-multiples' access to each other.

(See References, Section III).

WHEREAS multiple birth infants suffer elevated rates of birth defects and infant death:

- IV. Families experiencing the disability and/or death of co-multiples need:
- A) care and counseling by professionals who are sensitive to the dynamics of grief associated with disability and/or death in co-multiples; and

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B) policies which facilitate appropriate mourning of a deceased multiple or multiples

(See References, Section IV).

WHEREAS the unassisted care of newborn, infant, and toddler multiples elevates their families' risk of illness, substance abuse, child abuse, spouse abuse, divorce, and potential for child abuse:

- ٧. Families caring for multiples need timely access to adequate services and resources in order to:
- A) insure access to necessary quantities of infant and child clothing and equipment;
- B) enable adequate parental rest and sleep;
- facilitate healthy nutrition; C)
- D) facilitate the care of siblings;
- E) facilitate child safety;
- F) facilitate transportation; and
- G) facilitate pediatric care.

(See References, Section V).

WHEREAS families with multiples have the unique challenge of promoting the healthy individuation process of each comultiple and of encouraging and supporting a healthy relationship between the co-multiples; and, whereas the circumstance of multiple birth affects developmental patterns:

- VI. Families expecting and rearing multiples need:
- A) access to information and guidance in optimal parenting practices regarding the unique developmental aspects of multiple birth children, including the processes of: socialization, individuation, and language acquisition; and
- B) access to appropriate testing, evaluation, and schooling for co-multiples with developmental delays and/or behavior problems.

(See References, Section VI).

WHEREAS twins and higher order multiples are the subjects of myths and legends and media exploitation which depict multiples as depersonalized stereotypes:

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VII. Public education, with emphasis upon the training of professional health and family service providers, and educators, is needed to dispel mythology and disseminate the facts of multiple birth and the developmental processes in twins and higher order multiples.

(See References, Section VII).

WHEREAS twins and higher order multiples suffer discrimination from public ignorance about their biological makeup and inflexible policies which fail to accommodate their special needs:

- VIII. Twins and higher order multiples need:
- A) information and education about the biology of twinning; and
- B) health care, education, counseling, and flexible public policies which address their unique developmental norms, individuation processes, and relationship. For example by permitting and/or fostering:
- 1. the treatment of medically fragile co-multiples in the same hospital;
- the neonatal placement together of co-multiples in isolettes and cribs to extend the benefits of their fetal 2. position together;
- 3. medical, developmental, and educational assessment and treatment which is respectful of the relationship between co-multiples;
- the annual review of the classroom placement of co-multiples, and facilitation of their co-placement or 4. separate placement according to the particular needs of each set of co-multiples;
- 5. the simultaneous participation of co-multiples on sports teams and other group activities;
- 6. specialized grief counseling for multiples at the death of a co-multiple;

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7. counseling services addressing the special needs of adult multiples.

WHEREAS the participation by multiple birth infants, children, and adults as research subjects has made important contributions to scientific understanding of the heritability of disease, personality variables, and the relative influence of nature and nurture on human development; and, WHEREAS relatively little is known about optimal management of plural pregnancy and the unique developmental patterns of multiples:

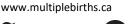
- IX. Scientists must be encouraged to investigate:
- A) the optimal management of plural pregnancies;

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- B) norms for developmental processes which are affected by multiple birth such as: individuation, socialization, and language acquisition;
- C) benchmarks of healthy psychological development, and relevant therapeutic interventions for multiples of all ages and at the death of a co-multiple.

Adopted by the Council of Multiple Birth Organizations (COMBO) (comprised of representatives of 16 organizations from ten countries: Australia, Belgium, Canada, Germany, Indonesia, Japan, Sweden, Taipei, United Kingdom, United States) (COMBO) of the International Society for Twin Studies at the Eighth International Twin Congress, Richmond, Virginia. May 31,1995

Patricia Malmstrom, Chair

Council of Multiple Birth Organization

Endorsed by the Board of the International Society for Twin Studies, May 31, 1995.

Lindon Eaves, President

International Society for Twin Studies

DECLARATION OF RIGHTS AND STATEMENT OF NEEDS OF TWINS AND HIGHER ORDER MULTIPLES

Adopted at the Eighth International Twin Congress, Richmond, Virginia. May 31,1995 by the COUNCIL OF MULTIPLE BIRTH ORGANIZATIONS, International Society for Twin Studies.

ENDORSING ORGANIZATIONS and REPRESENTATIVES, MAY, 1995:

Country/Organization/Name

#### Australia

LaTrobe Twin Study - David Hay

Australian Multiple Births Association - Maureen Copeland

#### **Belgium**

Association for Research in Multiple Births - Robert Derom

#### Canada

Parents of Multiple Births Association - Kim Johnson (former name for Multiple Births Canada)

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#### Germany

ABC Club - Ute Grutzner

#### Indonesia

Twins Foundation - Seto Mulyadi

#### Japan

The Japanese Association of Twins' Mothers - Yukiko Amau

#### Sweden

The Swedish Twin Society - Margareta Olwe

#### **United Kingdom**

Twins and Multiple Births Association - Rachel Hudson and Audrey Sandbank

Multiple Births Foundation - Elizabeth Bryan

#### U.S.A.

The Center for Loss in Multiple Birth - Jean Kollantai

The Center for the Study of Multiple Birth - Donald Keith

Illinois Mothers of Twins Clubs - Jean Herr

National Organization of Mothers of Twins Clubs - Rebecca Moskwinski and Marion Meyer

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